For illustration purposes: posed by model

OBSESSIONAL AVOIDANCE OF EVERYDAY DEMANDS

Phil Christie *introduces pathological demand avoidance (PDA), describes its symptoms in children and young people, and explains how therapists – and, through them, teachers and parents – can understand and work with it*

Pathological demand avoidance (PDA) was a term first used by Professor Elizabeth Newson in the 1980s. The initial descriptions of this profile showed a gradually evolving understanding of a group of children who had been referred for diagnostic assessment to the Child Development Research Unit at Nottingham University. Most of the children referred were complex and unusual in their developmental profile, and many reminded the referring professionals of children with autism or Asperger syndrome. At the same time, though, they were often seen as atypical in some way.

Newson and her colleagues felt increasingly dissatisfied with the description of 'atypical autism', feeling that it wasn't helpful in removing the confusion that was often felt by parents and teachers who were struggling to gain greater insight into the child's behaviour. As time went by it became apparent that, while these children were atypical of those with autism or Asperger syndrome, they were very similar to each other in some important ways. The central feature was 'an obsessional avoidance of the ordinary demands of everyday life'.[1] This was combined with sufficient social understanding and sociability to enable the child to be 'socially manipulative' in their avoidance. Newson proposed that PDA should be seen as a separate syndrome within the pervasive developmental disorders (PDDs), which was the recognised category used within the versions of the psychiatric classification systems current at the time (ICD-10, put forward by the World Health Organisation, and DSM-IV, by the American Psychiatric Association).

Characteristics of PDA

PDA is best understood as an anxiety-driven need to be in control and avoid other people's demands and expectations. Demand avoidance can, of course, be seen in the development of a number of children. It is the *extent* and *extreme* nature of this avoidance that causes such difficulties, which is why it has been described as 'pathological'.

Resisting and avoiding the ordinary demands of life
This is the feature of behaviour that gives the syndrome its name. Children can seem under an extraordinary

degree of pressure from everyday expectations, and they may attempt to avoid these to a remarkable extent. Demands might include a suggestion that it's time to get up, go out of the house or join a family activity. At times *any* suggestion made by another person can be perceived as a demand.

A key feature of PDA is that the child has sufficient social understanding to use a level of social manipulation in their attempts to avoid complying, and will often adapt strategies to the person making the demand.

These can include:

- distracting the adult
- acknowledging the demand but excusing self
- procrastination and negotiation
- physically incapacitating self
- withdrawing into fantasy
- physical outbursts or attacks.

Underpinning this avoidance is an anxiety about conforming to social demands and of not being in control of the situation.

Those with PDA may also use straightforward refusal or outbursts of explosive behaviour, including aggression. This is a form of panic on their part and is usually displayed when other strategies haven't worked or when their anxiety is so high that they will 'explode' or have a 'meltdown'. This can take the form of shouting, screaming, throwing things and physically lashing out, often in very sudden and dramatic ways.

Charlie's parents described how, at six years old, he wouldn't co-operate with simple day-to-day tasks such as getting dressed and feeding himself. The smallest of demands would initiate 'avoidance mode' and he spent a huge amount of time and energy fighting off the demand, when a fraction of that time and energy would have accomplished the task.

Charlie would offer an escalating amount of resistance. Initially he would giggle, tease and run away. If his parents weren't distracted, the resistance would become more definite and he might offer excuses such as, 'I'm busy… I'll do it in a minute… I want to do this first.' His next level would be to say, 'I feel sick… my tummy hurts' and so on. He would give reasons, such as it was too hard, too stiff or too heavy. If compliance was still pushed, then he became upset and tearful, followed by anger, shouting and throwing, finally throwing himself to the floor if the demand was not withdrawn.

Appearing sociable, but lacking depth in understanding

Children with PDA often appear sociable at first and 'people oriented'. They have often learnt many social niceties and may decline a request or suggestion politely. They usually seem well tuned in to what might prove effective as a strategy with a particular person.

At the same time, their social response is typically unsubtle and lacks depth. They can be misleading and overpowering, and may overreact to seemingly trivial events. They also have difficulty seeing boundaries, accepting social obligation and taking responsibility for their actions.

In addition, they often fail to understand the unwritten social boundaries or divides that exist between adults and children. They can become overfamiliar or come across as 'bossy'. They also seem to lack a sense of pride or embarrassment and can behave in very uninhibited ways.

Edward's parents talked about how he treated everyone the same. 'He's got no sense of authority and doesn't recognise a pecking order. He generally relates well to adults and responds better if you adopt an adult style of speech with him. He talks to other children as though he were in a teacher role, trying, for example, to stop children going out to play if it's raining. He treats his niece in the same way as his parents do, as though he were just another adult.

Excessive mood swings and impulsivity

Children with PDA can switch from one mood to another very suddenly, in a way that can be described as 'like switching a light on and off'. The emotions shown may seem very dramatic and over the top.

Difficulty with regulating emotions is common in all children on the autism spectrum, but is especially prevalent in PDA. Mood swings and impulsivity also persist beyond childhood in the majority of those with PDA. This switching of mood often seems to be driven by the child's need to control, and makes children with PDA very unpredictable.

Comfortable in role play and pretend, sometimes to an extreme extent

These children are often highly interested in role play and pretend. This was recognised early on as being different from other children on the autism spectrum. Children with PDA often mimic and take on the roles of others, extending and taking on their style, not simply repeating and re-enacting what they may have heard or seen in a repetitive or echoed way. Individuals with PDA, especially children, will often incorporate role play or pretend in the strategies that they use to avoid demands or exercise control.

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Language delay, often with a good degree of catch-up

The large majority of children with PDA are delayed in some aspect of their early speech and language development, although this may be dependent on their overall intellectual ability. This initial delay seems to be part of their overall passivity and there is often a sudden degree of catch-up.

They have more fluent use of eye contact and conversational timing than others on the autism spectrum. And, generally, they tend to have less difficulty in understanding non-verbal communication.

While the majority of these children become fluent in using expressive language, some have a problem with their understanding. They can have difficulty with processing what they hear and need additional time to do this – which can lead to misunderstandings and disruption to the communication process, which, in turn, can contribute to their behaviour issues.

Obsessive behaviour, often focused on people

This characteristic does not distinguish a child with PDA from others on the autism spectrum. However, Newson noted that the demand-avoidant behaviour itself usually has an obsessive feel.

Children with PDA may have a strong fascination with pretend characters and scenarios. The subjects of fixations can also revolve around specific individuals they interact with, and this can result in blame, victimisation and harassment that cause problems with peer relationships.

Jane Sherwin writes about her daughter Mollie in her book about parenting a child with PDA[2] and describes how Mollie became obsessed with her friend Gemma and treated her as if she were her child: 'She tried to control Gemma's every move and keep her isolated from the group… One particular meltdown at school happened because Gemma refused to use the toilet she had told her to use.'

Recent developments in clinical understanding and research

Newson's work on PDA attracted great interest as well as a degree of controversy. The overriding reason for the *interest* has been the strong sense of recognition expressed by both parents and professionals. Parents, in particular, recounted a 'light bulb moment' on reading the accounts, and a feeling that they were, at last, hearing a description that seemed to make sense of their child. The *controversy* that arose was about whether PDA existed as a separate syndrome within the pervasive developmental disorders or whether the behaviours could be explained within other diagnostic categories.

In the years following Newson's 2003 publication[1] – the first paper on PDA to appear in a peer-reviewed journal – it became apparent that the term autism spectrum disorder was being used as though it were the same as pervasive developmental disorder. The National Autism Plan for Children,[3] also published in 2003, talked about the term ASD 'broadly coinciding with the term pervasive developmental disorder'. The more recently published NICE guideline on autism spectrum disorders[4] described the two terms as being 'synonymous'.

The importance of this is that it is now increasingly recognised, by organisations including the National Autistic Society, that PDA is best understood as being part of the autism spectrum, or one of the autism spectrum conditions. The PDA society publishes an excellent resource for clinicians, as well as a number of other publications.[5]

However, it was also recognised that, despite the quality and detail of the clinical accounts and the strong 'recognition factor', there was a real need to underpin this with empirical research. Liz O'Nions, working with Francesca Happé, Essi Viding and others,

has carried out a number of studies over the last few years that have culminated in two articles being published: one in the *Journal of Child Psychology and Psychiatry*[6] and another in *Autism: The International Journal of Research and Practice*.[7] The first of these describes the development and preliminary validation of the *Extreme Demand Avoidance Questionnaire* (EDA-Q), which has the potential to quantify PDA traits to assist in the identification and differentiation of this group for further research.[8]

Guidelines for management and support

The accounts of PDA resonated with a large number of parents, teachers and other professionals, who were finding that many of their usual approaches, including tried and tested 'autism strategies', were proving less effective for children with this profile. Alongside the clinical descriptions, guidelines for education and management evolved that promoted an approach based on being less directive and more flexible than the more structured methods usually advocated for children with autism. These guidelines have since been developed, extended and adopted as part of the *National Autism Standards*, published by the Autism Education Trust.[9] They were taken further in the first published book about PDA.[10]

Underpinning the approach is the understanding that the child with PDA doesn't make a deliberate choice not to comply and can't overcome the situation by an act of will. He or she may, though, begin to make a series of achievements towards this end as trust and confidence build. Some key principles are listed below.

- The quality of relationships is fundamental. The relationship works both ways, and the child builds up and accumulates trust in the adult, becoming more confident in their ability to adapt accordingly.
- The style needs to be highly individualised but less directive and more intuitive than would ordinarily be the case with children with autism. Adults need to empower the child by giving more choices and, where possible, allow a feeling of self-control.
- Adults need to keep calm and level in their own emotions in the face of challenging or disruptive behaviour or situations that they may find frustrating.
- Novelty and variety is often effective because the child may exploit routine and predictability. Variety in the pace of presentation and personal style can intrigue the child.
- Drama and role play make use of the child's interest in imaginative play and can be used to depersonalise requests.
- Visual clarification methods (symbol strips, written messages, cartoon drawings etc) that are so successful for children with autism can also be useful for children with PDA, but often for slightly different reasons, in that they can be used in a way that depersonalises demands.

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- Expectations should be disguised where possible and reduced to a minimum. Confrontation should be avoided where possible.
- Ground rules need to be as few as possible but then maintained using techniques such as passing over responsibility (eg 'I'm sorry but it's a health and safety requirement'), depersonalising (through the use of imaginary characters, visual clarification etc) and giving choices that allow the child a feeling of autonomy.
- Choosing priorities regarding expectations and ground rules is critical. Reaching a consensus within a family or a staff team can itself be useful, as different individuals may well see different issues as important. For a time, some children may only have a few essential ground rules (perhaps linked to safety and welfare), which can then be extended as they become less anxious and more tolerant.
- Be flexible and adaptable. Strategies need to be changed much more frequently than for a child with autism. What works one day may not work the next, but it may be worth coming back to in the future.
- Using quite complex language can often be effective. This may go against the commonly accepted use of concise language styles for children with autism (based on an understanding of some of their processing and receptive language difficulties). Concise language can come across to the child with PDA as confrontational, while more complex language tends to feel more negotiative and may also intrigue the child.
- Humour can also be helpful and can be used to coax and cajole the child.
- Develop strategies that reduce anxiety. Techniques such as teaching relaxation, increasing the amount of physical exercise and giving the child a physical and psychological refuge within the school can all be valuable.
- Build personal understanding, self-esteem and emotional resilience. The curriculum in schools now gives a much higher priority to the concept of emotional literacy, which presents real opportunities for children with complex social and communication differences. As well as considering ways of reducing anxiety and supporting children on a day-to-day basis, it is crucial that those working with children and young people with PDA take a long-term, proactive view to helping build emotional resilience.

Individual mentoring sessions or personal tutorials[11] can be very effective in enabling children to develop self-awareness, self-understanding and appreciation of the consequences of their interactions and behaviours on other people. Over the last two or three years a number of publications have looked at how the principles of CBT can be adapted to support children on the autism spectrum.[12] Techniques such as social stories and comic strip conversations,[13] flow charts and mind maps can all be useful ways of discussing general principles (such as strengths and weaknesses, the nature of friendships etc). It has been shown that children with ASD, including those with PDA, can benefit greatly from this sort of work but that it needs to take account of their communication and learning style and requires more concrete visual presentation than is the case with many other children.

Those with a background in therapeutic approaches can make a great contribution in supporting the development of this sort of work in schools and other settings. Ideally, sessions should be carried out in a regular, systematic fashion, over a long period of time. This enables techniques to be developed that can be used in everyday situations, for example to manage arousal and emotions. They can also be useful, though, when carried out over fixed periods of time to help a young person deal with specific issues. Communication and liaison with those who have a longer-term involvement is critical in these situations.

Conclusions

Knowledge and understanding of PDA are still at an early stage, but there are exciting developments happening in diagnostic understanding, greater awareness of successful educational and therapeutic approaches, together with a perspective that is now being gained from further research. With all of these coming together, there is an opportunity for wider recognition of the condition as well as better understanding and support for individuals with PDA and their families.

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